



TESTIMONY OF DR. LEIGHTON CHAN
CHIEF, REHABILITATION MEDICINE DEPARTMENT
NATIONAL INSTITUTES OF HEALTH,
CLINICAL CENTER
BEFORE THE
UNITED STATES HOUSE OF REPRESENTATIVES
WAYS AND MEANS COMMITTEE
SOCIAL SECURITY SUBCOMMITTEE
MARCH 20TH, 2012

Chairman Johnson, Ranking Member Becerra, and Members of the Subcommittee, I am honored to have the opportunity to appear before you today to testify about the National Institutes of Health's collaboration with the Social Security Administration in studying approaches for analyzing function as it relates to disability assessment.

My name is Leighton Chan. I am the chief of the Rehabilitation Medicine Department at the NIH Clinical Center. I am a physician who specializes in the diagnosis and treatment of individuals with disabilities. I am also a researcher in the NIH intramural research program and have spent my career trying to identify and remove barriers to care for this vulnerable population.

Background on NIH-SSA collaboration

The SSA approached the NIH in August of 2007 for advice on new technologies, diagnostic tools, and novel assessment methods that might inform their disability evaluation process. The NIH Clinical Center's Rehabilitation Medicine Department agreed to help the SSA examine the disability determination process. Our collaboration has been facilitated by an initial Inter-Agency Agreement (IAA) that was executed in February, 2008. We anticipate that our work together will extend at least through 2016.

I want to note that our research at NIH in this area is one of many factors that the SSA takes into account in their statutory role to ensure the agency's disability evaluation standards reflect appropriate medical and vocational information.

Shifting paradigms of disablement

The way in which disability is conceptualized and measured has changed dramatically in the past 50 years, starting with the work of a distinguished medical sociologist, Saad Nagi in 1965. Over time, many others have built on Nagi's original framework. Prominent conceptual models of disability (Altman 2001) include those proposed by Nagi (1965, 1991), Verbrugge and Jette (1994), the Institute of Medicine (Brandt Jr. and Pope 1997; Pope and Tarlov 1991; Pope 1992), Abberley (1987), Oliver (1996, 1990, 1993) and the World Health Organization (1980, 2001). Although aspects of these models differ, they all agree that disability cannot be viewed as an individual attribute (Zola 1993). Disability may be thought of as the difference between individual capabilities and their environmental demands (Verbrugge and Jette 1994). The Institute of Medicine (IOM) (1991) noted that disability is not a stable attribute across situations, since physical and mental functioning is influenced by environments. Disability is a complex process, which is multidimensional, dynamic, and interactive in nature.

The World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF)

Debate about the concepts of disability culminated in 2001 when the WHO adopted a landmark standard called the International Classification of Functioning, Disability and Health (ICF) (World Health Organization 2001). The ICF has been officially endorsed by all 191 WHO members, including the United States. The ICF is a framework that provides a common language

to describe functioning as well as a comprehensive accounting of sub-domains of functioning, a feature that other contemporary models lack (see Figure 1).

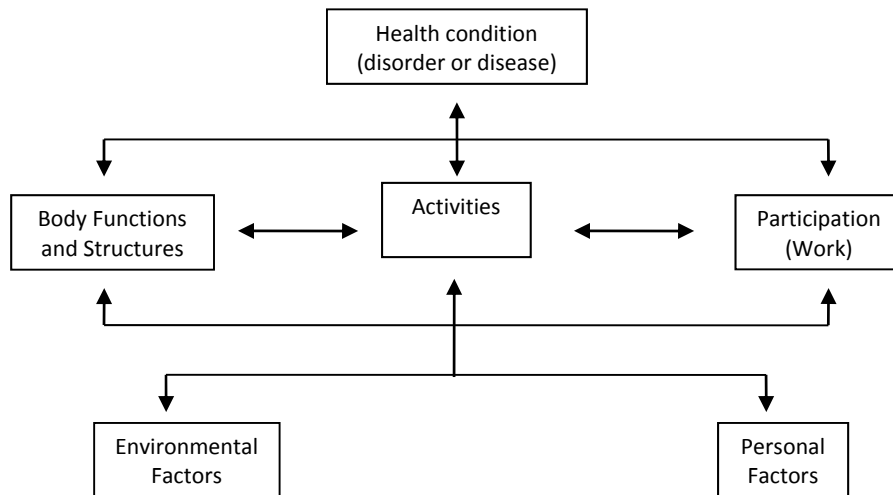


Figure 1: World Health Organization's International Classification of Functioning

The ICF is being integrated into important institutional frameworks in this country and abroad. In 2007, the Institute of Medicine (IOM) recommended that government agencies adopt ICF as a conceptual framework and language (Field and Jette 2007). This approach breaks through institutional and disciplinary boundaries that have long plagued disability research and inhibited cohesive efforts on behalf of persons with disability. The ICF now serves as the conceptual framework and terminology for the most recent edition of the American Medical Association (AMA) *Guides to the Evaluation of Permanent Impairment* (AMA Guides) (Rondinelli 2009).

The ICF is being taught in academic institutions to future generations of health care professionals and integrated into professional standards of practice by numerous professional organizations

including the American Psychological Association, the American Occupational Therapy Association, the American Speech-Language-Hearing Association, the American Physical Therapy Association, the American Therapeutic Recreation Association and the National Association of Social Workers. It is the ICF theoretical construct that informs the NIH collaboration with the SSA.

Research objectives

This collaboration has several components. One of the most important projects is to create a real time functional assessment that is rapid, reliable and objective. This project assesses the feasibility of developing Computer Adaptive Test (CAT) instruments that could be considered for integration into the SSA's disability evaluation processes. CAT methodology, coupled with Item Response Theory (IRT), is used to measure outcomes precisely across the full continuum of human functioning. IRT/CAT represents a simple form of artificial intelligence software requiring a computer for administration. We are working with researchers from Boston University (BU) on IRT/CAT development.

To illustrate: If you want to assess an individual's capabilities regarding a single characteristic, their ability to lift up 300 pounds in 1 pound increments, you could ask them up to 300 separate questions. This would provide a very precise assessment of how much that individual could actually lift but would take quite some time to figure out. Item response theory utilizes information gathered in prior questions to determine what question should come next, thereby eliminating many questions and saving time needed to assess an individual disability claim. For

instance, you might ask that same individual, can you lift 50 pounds? If the answer to that question is yes, the next question may be, can you lift 100 pounds? If the answer to this question is no, your next question might be can you lift 75 pounds? Within a short period of time you can determine how strong that person is.

An IRT/CAT is programmed first to present a question from the mid-range of a defined list of hierarchically ordered questions. The program then selects subsequent questions at an appropriate level based on the respondent's previous answers. Comprehensive calibrated question banks reflect a broad range of ability across each functional domain of interest. IRT/CAT administration permits the use of far fewer test questions (in total) because the questions are selected based on the individual's level of function. In the future, the utilization of IRT-IRT/CAT technology could potentially allow the SSA to collect more relevant, comprehensive, and precise data about human functioning in a faster, more efficient fashion.

The development of IRT/CAT tools is a sequentially dependent process that takes about two years. Each step of IRT/CAT tool development proceeds in an ordered fashion; one step must be completed before advancing to the next step. The first step of the process is the development of assessment questions. This step encompasses working with content experts, examining literature and reviewing other models/taxonomies to develop question content and structure. The next step is to calibrate the questions; order them from easiest to hardest and remove redundant or non-informative questions. Statistical analyses are conducted on data collected from samples of persons similar to the intended audience for the instrument. The objective is to assess the psychometric properties of the questions. The final step of developing IRT/CAT tools is to

validate the instrument. In our collaboration we plan to develop multiple IRT/CAT tool instruments. The content of each instrument is unique and development of each instrument must follow the sequential process. Examples of questions from the physical mobility IRT/CAT instrument we are developing include:

- Are you able to lift a full small (carry-on size) suitcase from the floor to table height?
- Are you able to stand up from a low, soft couch?
- Are you able to go up one flight of stairs with a handrail?

IRT/CAT instruments may be quite useful to the SSA. In addition to administering these tests to claimants, the SSA could also apply them to a clinician about a patient to obtain his or her functional assessment of the claimant. This could add an important perspective to a person's disability claim.

The SSA/NIH/BU collaboration is developing IRT/CATs tailored specifically for SSA's purposes -the assessment of work disability. This effort likely will yield a series of six IRT/CAT instruments to assess function. These assessment instruments will cover all the major ICF areas that are highly related to work, such as basic mobility, cognition, interpersonal interaction, communication, self care, and general tasks and demands.

The SSA/NIH/BU team is currently in the process of creating the first two IRT/CAT instruments. They will assess claimant's physical mobility and interpersonal interactions skills. These two were selected because of their high relevance to SSA's current applicant pool. For these domains, questions have been developed and preliminary testing is complete. Normative data are currently being collected using these question banks, after which, final IRT/CATs will

be developed. Data were collected from claimants as well as their health care providers. A request for proposal is currently posted for completion of the remaining IRT/CAT development activities. We hope to have much of our initial work for all six IRT/CAT instruments completed by 2016.

Mr. Chairman, this completes my prepared remarks. Once again, thank you for the opportunity to testify today and provide an overview of NIH's collaborative work with the Social Security Administration on the IRT/CAT program. I would be happy to answer any questions that you might have related to my work.

References

- Abberley, P. 1987. The concept of Oppression and the Development of a Social Theory of Disability. *Disability, Handicap and Society* 2 (1):5-19.
- Altman, B.M. 2001. Disability Definitions, Models, Classification Schemes, and Applications. In *Handbook of Disability Studies*, edited by G. L. Albrecht, K. Seelman and M. Bury. Thousand Oaks, CA: Sage Publications.
- Field, Marilyn J., and Alan M. Jette, eds. 2007. *The Future of Disability in America*. Washington, D.C.: The National Academies Press.
- Institute of Medicine. 1991. A Model for Disability and Disability Prevention. In *Disability in America: Toward a National Agenda for Prevention*, edited by A. M. Pope and A. R. Tarlov. Washington, D.C.: National Academy Press.
- Nagi, S.Z. 1965. Some Conceptual Issues in Disability and Rehabilitation. In *Sociology and Rehabilitation*, edited by M. B. Sussman. Washington, D.C.: American Sociological Association.
- Disability Concepts Revisited: Implications for Prevention. In *Disability in America*, edited by A. M. Pope and A. R. Tarlov. 1991. Washington, D.C.: National Academy Press.
- Oliver, M. 1990. *The Politics of Disablement: A Sociological Approach*. New York, New York: St. Martin's Press.
- Disability and Dependency: A Creation of Industrial Societies? In *Disabling Barriers--Enabling Environments*, edited by J. Swain, V. Finkelstein, S. French and M. Oliver. 1993. London: Sage Publications.
- Defining Impairment and Disability: Issues at Stake. In *Exploring the Divide: Illness and Disability*, edited by C. Barnes and G. Mercer. 1996. Leeds, UK: The Disability Press.

Pope, Andrew M. 1992. Preventing Secondary Conditions. *Mental Retardation* 30:347-354.

Pope, Andrew M., and Alvin R. Tarlov, eds. 1991. *Disability in America: Toward a National Agenda for Prevention*. Washington, D.C.: NATIONAL ACADEMY PRESS.

Rondinelli, Robert D. 2009. Changes for the New AMA Guides to Impairment Ratings 6th Edition: Implications and Applications for Physician Disability Evaluations. *PM&R* 1

Verbrugge, L.M., and Alan M. Jette. 1994. The Disablement Process. *Social Science and Medicine* 38 (1):1-14.

World Health Organization. 1980. *International Classification of Impairments, Disabilities and Handicaps: A Manual of Classification Relating to the Consequences of Disease*. Geneva, Switzerland.

International Classification of Functioning, Disability and Health. 2001, Geneva, Switzerland.

Zola, I.K. 1993. Disability Statistics: What We Count and What It Tells Us. *Journal of Disability Policy Studies* 4 (2):9-39.